



RE: [HF 988](#) **Rare Disease Advisory Council Appropriation**
ATTN: Minnesota House Human Services Finance Committee
Date: February 9th, 2023

Chair Noor and Members of the Committee,

The Minnesota Council on Disability urges you to support HF 988 which provides an ongoing appropriation to the Minnesota Rare Disease Advisory Council to hire staff and develop their newly formed agency.

Because *rare* diseases are rare, it can be a challenge to get the support and advocacy needed to raise awareness and find treatments for them individually. Often people with diseases must rely on a wealthy or political affluent family with a connection to their disease to get the attention of doctors and research institutions to address their disease. However, collectively, rare diseases are actually common. There are about 7,000 known rare diseases and about 1 in 10 people (or 30 million people) in the U.S. have a rare disease.

The Minnesota Rare Disease Advisory Council plays an important role in advocating for all rare diseases. They also help those with rare diseases collectively expand their influence on and lift their voices to elected officials, universities, hospitals, and research institutions. They give those without wealth or political affluence a chance to fight their disease with more resources and support from the entire rare disease community. The Rare Disease Advisory Council is a leader in improving the lives of those with rare diseases and ensure their stories are in fact heard.

The Minnesota Council Disability supports HF 988 because Rare Diseases are protected under the Americans with Disabilities Act and the Minnesota Human Rights Act. Not all disabilities are due to a rare disease, but many rare diseases manifest themselves as disabilities. We urge the members of this committee to support this legislation and support Minnesotans with rare diseases.

Sincerely,

Trevor Turner
Public Policy Director
Minnesota Council on Disability